

TESTIMONY
BY THE
NATIONAL ALLIANCE FOR THE MENTALLY ILL

ON THE REAUTHORIZATION
OF THE SUBSTANCE ABUSE AND
MENTAL HEALTH SERVICES ADMINISTRATION

FOR
THE HOUSE COMMERCE COMMITTEE
SUBCOMMITTEE ON HEALTH & THE ENVIRONMENT

The Honorable Michael Bilirakis, Chair

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Room 2123 Rayburn House Office Building

On behalf of the National Alliance for the Mentally Ill (NAMI) and its 140,000 members who are families of people with severe brain disorders as well as those people themselves, I am pleased to present testimony on the reauthorization of the Substance Abuse and Mental Health Services Administration (SAMHSA). I am Fred Frese, a national Board Member of NAMI, and a long-time consumer of mental health services.

Persons who suffer with severe brain disorders are still targets of stigma and discrimination. Despite the significant progress made with public opinion during the health insurance debates of the last Congress, pervasive discrimination sadly remains. Discrimination in private sector health insurance results in dumping onto the public systems. NAMI has undertaken a multi-year campaign against discrimination. We commend Secretary Shalala for making an attack on discrimination a priority for HHS.

NAMI is concerned, as are other associations that advocate around chronic diseases, about the rapid modifications of the healthcare system in the U. S. In both private and public sectors, this unrelenting change is seriously affecting access to clinically appropriate treatment and services for persons suffering from severe and persistent brain disorders. A second round of Medicaid waivers is placing persons disabled by severe and persistent brain disorders into managed care contracts for their needed treatment and services. The effective specialty services developed by the public systems are neither adequately understood nor sufficiently funded in many such contracts.

The Center for Mental Health Services is the principal agency of the federal government charged with advising the Health Care Financing Administration (HCFA) and developing and disseminating information and technical assistance to intervene in the change to protect vulnerable consumers from loss of treatment. NAMI has a substantial interest in a number of programs and initiatives of the Center for Mental Health Services (CMHS). We will address each of these in this testimony.

Size of affected population; effects on society

There are 5 million adults, 2.8% of the population, afflicted with severe brain disorders in any year. A National Institute of Mental Health Advisory Council report lists the most

severe disorders as schizophrenia, bi-polar disorder, major clinical depression, obsessive-compulsive disorder, and panic disorder. We at the National Alliance for the Mentally Ill call these illnesses, correctly, *brain disorders* and will so refer to them for the remainder of this testimony. They are real illnesses, and they are treatable.

These brain disorders can be so disabling that despite the rigorous eligibility determination process, the Social Security Administration allows millions of cases. The Supplemental Security Income program, and the Social Security Disability Insurance program each have over 25% of their enrolled beneficiaries there because of a "mental diagnosis other than mental retardation."

Early and effective treatment could prevent persons from becoming so disabled. Alternately, new medications and supports can help persons return to work, if the employment doesn't perversely cause the loss of the very medications and supports that made the employment possible.

History of community treatment

When policies of the federal government fostered deinstitutionalization decades ago, there was no immediate, effective public sector follow-up to create community networks of services to support the persons released from hospitals. But such networks have been developed since, with the help of the Community Support Program (formerly in NIMH, now in CMHS) and its inclusion of consumers and families in designing and monitoring such networks. CSP affirmed the prioritizing of resources for the most seriously ill consumers.

NAMI urges the insertion of language into the reauthorizing legislation which would direct States to prioritize services to adults and children with the most severe brain disorders.

State Mental Health Authorities helped to enlist Medicaid resources in the building of community networks. The SSI-Medicaid eligibility link and the optional services states could choose to include in their Medicaid plans came together to significantly enhance non-institutional medical and support services for persons with severe brain disorders. Optional services such as intensive case management and psychosocial rehabilitation are utilized in forty or more states. These community-based services are under intense assault

currently, as states move to include disabled persons in a second wave of Medicaid managed care waivers.

Role of the Center for Mental Health Services

The presence of the Center for Mental Health Services in HHS fills an appropriate federal role for the protection of citizens. CMHS should be able to do more in this essential area. The Health Care Financing Administration must also exercise this citizen protection function. But the concentration of professional expertise about services that work for persons with brain disorders is at the Center for Mental Health Services.

CMHS is currently studying the widely divergent actuarial estimates for the cost of parity that emerged during last year's debate on the Domenici-Wellstone parity amendment to develop more common assumptions and work toward greater convergence of such estimates in the future. CMHS is also analyzing the outcomes for consumers of managed care in six states.

Important work of this kind is being conducted not within any of CMHS' program line items, but within its operations budget, which accordingly should be increased.

Mental Health Planning Councils/Family & Consumer participation

NAMI is pleased that the proposed legislation would maintain the important contribution of families and consumers on State Mental Health Planning Councils. These councils play an important role in developing comprehensive state mental health plans, reviewing implementation and compliance with these plans, and in advising States as to how best to serve adults and children with severe brain disorders. The role of these planning councils increases in importance today, given the wholesale changes which are occurring in the configuration and financing of public mental health services.

NAMI is also pleased that the reauthorization legislation retains the critically important function of planning councils to review and *independently* comment to the Secretary on the State's annual plan submission for block grant funding. The Administration's proposed addition of authority for the Councils to review and comment on the annual progress reports as well as a provision NAMI strongly supports and applauds.

We would like to see these Councils given similar independent oversight regarding Medicaid changes that affect services for persons with severe brain disorders, though we realize that is not at issue in the PHS Act.

NAMI believes strongly that the effectiveness of these planning councils very much depends upon their ability to retain independence from the state mental health agency. This independence is enhanced by maintaining the requirement in federal law that these councils must include substantial representation of families and consumers, and must not be made up of more than half providers and state employees. We therefore urge that this requirement be highlighted in the reauthorizing legislation.

Although State mental health authorities should not have control over planning councils, these authorities nevertheless play an important role in training and orienting families and consumers to the roles and functions of these planning councils. If they are not briefed, furnished with readable documents in layman's language, and oriented to procedures -- families and consumers will not be able to come to the table as prepared participants, who will not be cowed by the providers, government officials, and health planning professionals who make up the remainder of the council.

An additional important role for State mental health authorities is the financing of travel and related expenses incurred in traveling to meetings of these planning councils, since consumers and families often do not have the resource to finance their own travel and expenses related to participating in a meaningful sense in these activities.

Projects for Assistance in Transition from Homelessness (PATH)

The PATH program was authorized in 1990 as a program targeted to link comprehensive, community-based services with housing for individuals who are homeless and severely mentally ill, including those people who suffer from co-occurring severe brain disorders and substance abuse disorders. In FY 1994, over 127,000 individuals received services supported by PATH such as outreach, case management, screening and diagnostic treatment, rehabilitative services, and referral services which are vitally important for addressing the needs of the target population.

Although PATH has never been fully or adequately financed, it is generally regarded as an effective program in addressing the multiple needs of people who are homeless and severely mentally ill. States are required to match every \$3.00 of Federal assistance received with \$1.00 State funds (cash or in-kind). In fact, States have far exceeded the minimal matching requirement, providing, on the average, in excess of \$3.00 for every \$3.00 in Federal PATH funds.

Since PATH is an effective program which has suffered from being underfunded, we urge that PATH be reauthorized at the same level of \$75 million as the previous authorization.

Block grant must allow for family and consumer activities

NAMI believes that family and consumer outreach and education are a very legitimate and necessary use for funds made available to the states through this act. The growth of family education, and peer support over the last decade has undoubtedly made a significant contribution to the reduction of inappropriate hospitalization, with substantial cost savings. Given the insufficiencies at the community level of community housing and rehabilitations services, the role of family as caregiver should be strongly supported by SAMHSA.

In a changing health environment, the importance of consumers and families as monitors of adequacy and quality of treatment assumes even greater importance. There should also be a strong federal interest in the participation of families and consumers in review and comment on reconfiguration of public service delivery systems.

There must continue to be federal support available to assist consumers and families to fulfill this important role. An ***amount no less than \$7 million*** should be available under the block grant for family and consumer outreach and education.

"Knowledge development and application"

NAMI supports the notion that service model demonstrations should be scientifically sound. Effective demonstrations can contribute to the overall knowledge base concerning services that work. NAMI supports the intention to spread what we know works through the Knowledge Development and Application (KDA) mechanism. Priority should be given

to the "application" of the best service models. The CSP service model is foremost among these. Assertive community treatment belongs here as well.

Over the last decade and a half the Community Support Programs, operated under demonstration authority, together with the outgrowth of the consumer and family involvement formed the basis for much of the community care effort. They were the source of innovation, focussed on the priority population of the severely ill. The CSP programs asserted leadership both in policy and in practice. The continuation of this potential must be secured.

CMHS has several on-going demonstrations that are very targeted on the special needs of adults with severe brain disorders. NAMI is very supportive of the CMHS-supported demonstrations on housing, employment, and treatment of co-morbidity. NAMI has recently released a report on the shortcomings of the Vocational Rehabilitation system in serving the employment needs of persons suffering from severe brain disorders.

We also note favorably that demonstrations are being done *jointly* by CMHS and the Center for Substance Abuse Treatment (CSAT) on jail diversion, and on homelessness.

A significant proportion of demonstration resources, under the new, more rigorous rubric, must continue to prioritize the most seriously ill and must be accessible to consumers and families. Authorizing legislation should allow for appropriations up to \$73 million.

Co-morbidity issues

NAMI believes that the prevalence of a brain disorder and an addictive disorder in the same person is so common that SAMHSA should pay much more attention to it. We are pleased that the Administrator has raised its priority. Persons with dual diagnosis are a very underserved, high cost population. They are disproportionally represented in jails and prisons, and are more prone to violent behaviors. A severe and persistent brain disorder cannot be adequately diagnosed while a person is actively experiencing symptoms of drug addiction. The person needs to go through detoxification in order to make possible a good assessment and diagnosis of underlying disorder(s). In the past, service systems in the field that are supported through the two sides of SAMHSA have paid virtually no attention to this problem.

CMHS has funded two mental health programs to treat addictive disorders, and two substance abuse programs to treat brain disorders. This set of grants requires both types of service agencies to re-configure their staff skills and credentials to deal with the other co-occurring disorder. It's a modest beginning, but in the right direction.

The reauthorization of SAMHSA should require a significantly increased effort in this area. Minimally, each of SAMHSA's two substance abuse centers should fully match the amount CMHS is investing in demonstrations on treating dual diagnosis, as part of a jointly planned initiative.

Balance of resources within SAMHSA

NAMI believes that a single CMHS KDA authority can work profitably for the development of knowledge on service systems of treatments and supports that work for persons with severe and persistent brain disorders. As new medications continue to be approved for public use, support systems may require modification.

Dual diagnoses are so prevalent in the populations treated by both service systems that much more should be invested from the Substance Abuse side to learn about models that work in addressing both diagnoses. Most if not all support for such demonstrations now comes from the Mental Illness side -- which has only 10% of the total demonstration authority dollars. The funding level of the Mental Health block grant has been static for years, while the Substance Abuse block grant continually increases.

NAMI believes that the imbalance of resources between Mental Illness and Addictive Disorders must be addressed in reauthorization.

Protection & Advocacy

People with severe brain disorders remain particularly vulnerable to abuse and neglect in all aspects of their lives. We receive calls on a daily basis from consumers and family members reporting abuse or neglect in a variety of settings, including hospitals, jails and prisons and community-based programs. In most States, Protection and Advocacy programs are the only source of assistance available to these people. These programs must put renewed emphasis into individual advocacy (even at the expense of class action

lawsuits) and into advocating for people with severe brain disorders who are in jails and prisons or in homeless shelters or other similar community-based settings.

Although some progress has been made, NAMI remains concerned that many Protection and Advocacy workers do not adequately understand the nature of severe brain disorders and the problems experienced by people who suffer from these illnesses and their families.

Therefore, NAMI urges Congress to direct all State Protection and Advocacy programs to incorporate meaningful consumer and family participation in program governance and in training activities.

Once again, NAMI appreciates this opportunity to testify for the Subcommittee on the reauthorization of SAMHSA, and to bring to you the profile and the needs of persons with severe brain disorders who are dependent on publicly financed service systems for the medical treatment and supports that permit them to live in the community.

Respectfully Submitted,

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National Board Member

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NAMI has received \$36,642 of support in grants from the National Institute of Health, and the Center for Mental Health Services during *our* current (July - June) fiscal year. NIH support for biomedical policy research totalled \$7,622. CMHS supported consumer participation in our convention at a level of \$19,000. CMHS supported our state initiative at a level of \$9,980.